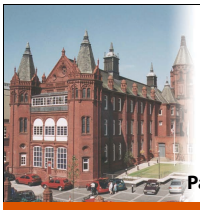

GENERAL PRACTITIONERS' AND BEREAVED FAMILIES' EXPERIENCES OF PALLIATIVE AND BEREAVEMENT CARE FOLLOWING THE DEATH OF A CHILD FROM CANCER: INTERIM FINDINGS

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Introduction

The rarity of childhood cancer deaths makes it difficult for GPs to develop or maintain palliative care knowledge and skills yet the GP is perceived as the gatekeeper for care within the community.

Study aim and objectives

Aim: To examine what a GP perceives their role to be in caring for an individual child with cancer receiving palliative care and compare with what families' perceive the GP roles should be.
Objectives:
To Identify factors negatively impacting upon GP role development.
To Identify aspects of GP's roles perceived as positive and that could be transferred across palliative care provision generally.
To examine discrepancies in role perceptions.
To identify the potential to enhance the role for the paediatric oncology outreach team in supporting GPs.

Methods

Phase 1
1:1 semi-structured interviews with 18 general practitioners and 11 bereaved families.
Thematic concept analysis.

Phase 2
Q-methodology : 30 GPs are being asked to rank statements drawn from the thematic analysis of the interview data according to their level of agreement. Factor analysis will be undertaken on the rankings and the level of subjectivity of the factors then examined.

Examples of interim findings from interview data

GP Perspectives

Identified roles included writing prescriptions, supporting family, co-ordinating care. A wide variation in GP experience was found.

I will look back on it as a golden time of proper old fashioned general practice because I feel that ... our input made a difference (GP 8)

With pressures on time within general practice it's getting increasingly hard to do the job as it should be done (GP 1)

Symptom Management

The majority of GPs welcomed support from the specialist team.

The GP was the one who had to medicate for the syringe driver ... he needed to be talking to the consultant, me and the community nurse on both the symptoms and the previous medication ... (Family 8)

I was terrified I was going to be in charge of a syringe driver prescribing for a 2 year old (GP 14)

Regional / Shared Care Centres

The regional or shared care centre managed the child's care during active treatment, the GP having little or no contact.

You couldn't get a relationship with them because you didn't know them (Family 9)

... if I'd known her from diagnosis, kept regular contact, I think that would have made that transition into providing palliative care ... less awkward (GP 14)

Out of Hours

Out of hours care was not always provided by the family's GP.

I didn't want anybody from the on-call doctors coming (Family 4)

I never want the family to feel ... they don't know what to do, they don't know who to call so I'm always available for all my terminal care patients 24 hours a day, seven days a week, they have my mobile phone number (GP 17)

Family Views of GP

The importance of good communication and face to face contact with the GP was highlighted by families.

I knew my GP had not been in that situation and that was absolutely fine ... because they were open about it. ... had they pretended they knew it would not have reassured me (Family 8)

It would have been nice for (GP) to have (seen the child before they died) rather than just come at the end to sort the certificates (Family 21)

Summary

Phase 2 of the study is on-going and it is anticipated that the data collection will inform these interim findings.

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